



SETTING PRIORITIES FOR TYPE 1 DIABETES RESEARCH – WORKSHOP

Report of a workshop held on the 24th May 2011 at Friends House, London

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dedicated to finding a cure



1. The Type 1 diabetes Priority Setting Partnership

The James Lind Alliance (JLA) type 1 diabetes Priority Setting Partnership (PSP) was established in early 2010, following an exploratory workshop in June 2009. It began its process formally by launching a survey of treatment uncertainties in type 1 diabetes at the Diabetes UK Professional Conference in March 2011. It completed with the final priority setting workshop in May 2011, where a top 10 list of type 1 diabetes treatment uncertainties for research were agreed by patients and clinicians.

The Insulin Dependent Diabetes Trust provided core funding for the project, with other partners contributing time and expertise in kind; including production of survey materials, distribution of update reports etc

1.1 Partners

The partnership includes; Juvenile Diabetes Research Foundation, Insulin Dependent Diabetes Trust, Diabetes Research Network, Diabetes UK, Scottish Diabetes Research Network, UK Database of Uncertainties in the Effects of Treatments (DUETs) and the James Lind Alliance (JLA), NHS Evidence – diabetes (until March 2011). There were individual members with perspectives in paediatrics, primary care and using type 1 diabetes services.

A Steering Group of representatives from these organisations, met to plan the whole process, including the final priority setting workshop.

2. The workshop

2.1 Workshop objectives:

1. *To give an overview of the priority setting process and work so far*
2. *To reflect on, and discuss participants' views of the type 1 diabetes treatment uncertainties short list*
3. *In small and larger groups priority order the short list, noting areas of agreement and disagreement across groups, together agree the 10 most important treatment uncertainties*
4. *Consider next steps, so that the 10 are taken forward for research funding.*

2.2 Workshop participants

23 people participated in the workshop: 7 people with type 1 diabetes; 3 carers/parents of people with type 1 diabetes, 3 Clinicians; 1 nurse; 2 other professionals; 3 diabetes charity representatives (one of which is also a parent of someone with type 1 diabetes) 1 observer and 3 JLA facilitators.

2.3 Pre workshop request of participants

During the workshop most of the discussion about type 1 diabetes research was in groups. However all participants were sent the shortlist so that they could individually reflect on the research questions prior



to the workshop. They were encouraged to record their views and comments on each of the questions, and rank them in order of priority. This had a dual purpose; it enabled participants to be familiar with the research questions under discussion, and ensured that everyone had something to contribute in the first discussion session.

2.4 Workshop content

Sally Crowe from the JLA welcomed everyone and acknowledged the hard work that the steering group had done to get to this, final priority setting point. She outlined the workshop objectives, the role of facilitators and observers, and gave an overview of the survey process and results.

Type 1 diabetes survey

583 respondents submitted a total of 1141 treatment uncertainties, 95% of the respondents have given permission for their uncertainties to be published in UK DUETs <http://www.library.nhs.uk/duets/>

The profile of survey respondents was:

- 71% identified as a person with type 1 diabetes
- 10% said they were a carer/relative
- 13% were the parent of a child aged under 16 who has type 1
- 5% were a health professional based in primary care
- 11% were based in secondary care
- 5% said they were part of an organisation representing people with type 1 diabetes
- Of the health professionals, 50 work in an adult setting, 49 work in a paediatric setting, and 18 said they work in both
- Age of the respondents with type 1, or those on whose behalf they are responding, the breakdown is as follows: 6% are aged 0-9, 13% are 10-19, 19% are 20-29, 24% are 30-39, 17% are 40-49, 14% are 50-59, 9% are 60 or over.
- Age of diagnosis: 32% at age 0-9, 33% at 10-19, 18% at 20-29, 10% at 30-39, 3% at 40-49, 2% at 50-59 and 0.5% at 60 or over.
- Ethnic breakdown is as follows: 93% White, 0.5% Black, 3% Asian, 2% mixed race and 0.5% Chinese/other
- 61% of respondents were female, and 39% were male

546 individuals were kept informed of progress – with some taking part in subsequent priority setting activity.

Processing the survey responses

Ann Daly, an independent information specialist outlined the work done to process the survey results. Key points included:



- Agreeing categories that the treatment uncertainties belong in, and where there was duplication in submissions
- Agreeing the wording of ‘indicative’ uncertainties to reflect groups of submissions
- Converting all questions to ICPO standard (Intervention, Comparison, Patient and Outcome)
- Removing uncertainties that were not concerned with treatment of type 1 diabetes - 251
- Adding in current uncertainties from research recommendations and ongoing research + 118 (source UK DUETs)
- Removing all single unique submissions – 222
- Calculated responder prevalence to help get a feel of which groups (patients, carers, professionals, organisations, etc.) were submitting particular uncertainties.
- Everything with more than one response = a ‘long list’ of 88 type 1 diabetes treatment uncertainties
- Identifying where existing systematic reviews currently exist that answer the research questions (there were none that adequately answered any on the long list)

Initial prioritisation

The Steering Group reviewed the long list of 88 and decided that everything with more than 10 submissions plus some considered important by SG should form the interim voting short list = 47

The 47 item list sent out for voting (10 votes per person), there were 46 returns (with one unusable) split roughly half between clinicians and patients. The Steering Group agreed that everything with over 10 votes would be shortlisted for the workshop, resulting in a pre workshop list of 25 treatment uncertainties.

Reflections on the process so far

Martin Lodemore who has been representing the Diabetes Research Network on the PSP described his observations of the process so far including:

- ▶ Dealing with ‘raw’ questions sometimes a challenge, such as identifying any overlap, recognising nuances/subtleties within questions, splitting those with 2/3 questions in a submission, taking care to avoid putting our interpretation on ‘raw’ questions
- ▶ All queries were taken back to group for discussion
- ▶ Partnership members worked without bringing own ‘agendas’

Sally invited questions and points of clarification at this stage. Participants were then placed into three facilitated groups each with a balance of clinician/professional, carer/patient participants.



Round 1 discussions (11.00 – 11.30)

This round focussed on the similarities and differences between the individual rankings with people beginning to appreciate the different (or similar!) points of view. All participants brought their pre workshop ranking forms and had clearly given this stage of the process due care and thought. Facilitators were briefed to ensure that everyone had an opportunity to say something about their list before the end of this session.



Round 2 discussions: (11.50 – 12.45) same three groups

This round focused on creating a group rank order of all the shortlisted treatment uncertainties. Facilitators used cards provided to position them where there was already consensus, and/or to reflect the discussion in the first discussion. Group members were encouraged to handle the cards, read the contextual and previous voting information on the back, and move the cards around according to group views.

Agreed ranking of treatment uncertainties was recorded by using the ID of letter/number and handed to Lester Firkins who was in charge of collating all the ranks from the four discussion groups. After lunch Lester Firkins presented the groups scores and the aggregate score so far. Participants were encouraged to challenge other groups about their choices, and appraise the aggregate rank order together.

Round 3: (13.30 – 15.00)



The participants decided to work as a plenary group for the rest of the workshop; at 17 participants with voting rights this was manageable. The current aggregate rank list of the uncertainties were placed on the floor and the participants gathered round for the discussion. Working with an aggregate list can be challenging but participants *have to accept this it is part of consensus development*.

The sort of issues that emerged in the final session was very interesting and included:

- The need to balance the top ten with research questions that explore new territories in type 1 diabetes and addresses current regimens of treatment
- Stem Cell research was felt to be a vitally important area of research into the cure of type 1 diabetes and that it was difficult to articulate a single question from the submissions. Everyone agreed that the potential for this therapy and results were still many years away – therefore so as not to waste a place on the top ten this was given ‘overarching status’ of the priority setting process.
- Some questions were deemed similar and groups in the pre lunch sessions had dealt with this differently, so these were discussed in detail and the most popular questions agreed.
- Clarification of certain uncertainties and agreeing commonly used terms

Round 4 15.30 onwards

Following a well earned refreshment break the large group session was re-convened. Participants were asked to focus on the top ten at this stage and it was a final opportunity for participants to make a case for any particular uncertainty and its placing.



Participants were reminded that **all of the uncertainties** are a resource for researchers, including the original dataset, the shortlist and the top ten.

3. Workshop results - Final Top 10 type 1 diabetes treatment uncertainties

Q		OVERARCHING RESEARCH ASPIRATION FOR TYPE 1 DIABETES An effective cure for type 1 diabetes
1	C	Is it possible to constantly and accurately monitor blood sugar levels, in people with type 1 diabetes, with a discrete device (<i>non-invasive or invasive</i>)
2	U	Is insulin pump therapy effective? (<i>immediate v deferred pump, and comparing outcomes with multiple injections</i>)
3	M	Is an artificial pancreas for type 1 diabetes (closed loop system) effective?
4	T	What are the characteristics of the best type 1 diabetes patient education programmes (from diagnosis to long term care) and do they improve outcomes?
5	I	What are the cognitive and psychological effects of living with type 1 diabetes?
6	L	How can awareness of and prevention of hypoglycaemia in type 1 diabetes be improved?
7	O	How tightly controlled do fluctuations in blood glucose levels need to be to reduce the risk of developing complications in people with type 1 diabetes?
8	S	Does treatment of type 1 diabetics by specialists (e.g. doctors, nurses, dieticians, podiatrists, ophthalmologists and psychologists) trained in person-centred skills provide better blood glucose control, patient satisfaction and self-confidence in management of type 1 diabetes, compared to treatment by non specialists with standard skills?
9	E	What makes self management successful for some people with type 1 diabetes, and not others?
10	V	Which insulins are safest and have the fewest (<i>long term</i>) adverse effects?



4. Workshop Evaluation

The Type 1 Diabetes PSP final workshop took place on Tuesday 24th May 2011. The following paper summarises the feedback provided by participants who completed a workshop evaluation form at the end of the day. A total of nine forms were received from six patients/patient representatives, one carer, one clinician and one clinician researcher. An additional online evaluation of the whole priority setting process will also be carried out.

- The pre-workshop pack was emailed in advance of the workshop to help people prepare. Six participants found it helpful and the remaining three found it very helpful.
- Everyone was satisfied with the way the JLA team facilitated the workshop, with six stating that they were very satisfied.
- Everyone was satisfied that they were able to communicate their views in the workshop, including five who were very satisfied.
- Four participants were very satisfied that their views and preferences shaped the final list of treatment uncertainties, four were satisfied and one was neither satisfied nor dissatisfied.
- Five were satisfied and two were very satisfied with the workshop outcome of establishing the top ten treatment uncertainties for research. Two were neither satisfied nor dissatisfied.
- Everyone was satisfied with the venue for the workshop, with five being very satisfied.

The following comments were made about the workshop:

- Interesting.
- Excellent, thank you.
- Very good all round experience. Good use of the day.
- Found some of the questions difficult to work with but happy with the outcome.
- The questions were poor - too vague, too specific or duplicating other questions. Writing them with a Diabetes specialist might have improved them.
- A shame that the steering committee formulated/worded several questions that were so similar - it meant voting between them and either relegating one (although it was low priority) or including both, and thus displacing another important topic.
- Quite a few people worked very hard to organise the workshop. Personally I found it helpful and informative. Hopefully funding will be found to further our questions. Thank you for inviting me.

Subsequent email feedback after the day included:

"the organisation and people-management was really impressive"

"it was a pleasure to be able to help with the very important research for Type 1 diabetes. It was an excellent opportunity to meet other patients as well as carers, clinicians, researchers and doctors"

Areas for improvement for the JLA's Monitoring & Implementation Group to discuss are therefore:

- A standard procedure for ranking together or relegating uncertainties which participants feel are similar
- What else can be done to ensure a steering group's choice of question wording is as unambiguous as possible?



4.2 Longer term evaluation of Priority Setting Partnership

On completion of the JLA process, each PSP member, and participants in any aspect of the process were asked to feed back their views on how the process itself worked for them, via an anonymous online survey. This was an opportunity to identify strengths and weaknesses in the process, following a period of reflection from partners. Data captured by the survey will be used by the JLA to inform, develop and improve future PSPs, and when compiled will be available on the JLA website.

Two people were not sure if they would recommend the process, because they were uncertain how applicable it would be to other conditions in their field. One person said they would not recommend it due to it being a “long-winded” process. They were unsure that the process was truly bias-free.

5. What next for priorities?

Participants agreed the following next steps – with some offers of help to the PSP to achieve them.

- Publishing the top ten and rest of the shortlist on UK DUETs, and working to publish the remainder of the uncertainties over time
- Working on the priorities to get them into more robust research questions
- Targeting research funders, and the DRN Clinical Studies Advisory Group with the priorities
- Sharing the priorities more widely, once **the top ten and shortlist uncertainties have been published on UK DUETs.**
- Producing a factual report of the workshop that can be used as source text for articles and publications
- Roger Gadsby will lead in writing a publication on the process and outcomes for Diabetic Medicine Journal
- The James Lind Alliance and UK DUETS will support this work and monitor progress

6. In conclusion

Thanks to all of the Steering Group members of the Priority Setting Partnership for helping to plan and organise the event. Thanks to Ann Daley and Martin Lodemore for preparing the data and presentations on the day. Most thanks go to the participants who gave a whole day to the effort of reviewing research priorities in type 1 diabetes, with energy, humour, and breadth of experience and insight that proved invaluable on the day.

